

OFFICE OF NEWBORN SCREENING

Arizona EHDI Connection

Volume I, Issue 3

October 2011

Special points of interest:

- Fostering Communications with Providers
- Is Your Office EHDI-Ready?
- Why Reporting is So Important
- ASDB Early Childhood and Education Program

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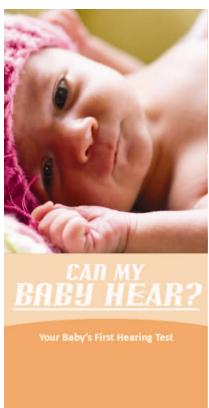
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NEW! Newborn Hearing Screening Brochure



A new hearing screening brochure for parents, titled "Can My Baby Hear? Your Baby's First Hearing Test," is now available. This brochure is a tool for parents that will educate them on the importance of the newborn hearing screen. The brochure includes information (English and Spanish) on:

- · How the hearing screening is performed,
- What to do if the baby passes or does not pass the screening,
- What to do if a baby is at risk for hearing loss, and
- A milestones chart to check baby's hearing, speech and language development.

Office of Newborn Screening staff worked with consulting audiologists, the Arizona Chapter of the American Academy of Pediatrics Best Care for Kids, and the EAR Foundation of Arizona to ensure that the brochure would provide valuable information for parents and providers. The Arizona Chapter of the American Academy of Pediatrics Best Care for Kids staff conducted a survey with parents to get their input on the brochure. Feedback received from parents was positive.

"Can My Baby Hear? Your Baby's First Hearing Test" is available for hospitals, healthcare providers, and any healthcare professional who works with infants, free of charge. Please visit the Office of Newborn Screening website at www.aznewborn.com, or call (602)364-1409/(800)548-8381 to order brochures.

Putting the eLearning Curriculum to Work!



Originally I wanted to participate in the eLearning course to evaluate it as a competency for our staff. As I started with the modules, I was amazed by the information I was receiving. Not just the "How" of performing screenings, but most importantly, the "Why." Not just the simple "Why," but the life-changing, long-term effects that could be prevented with early detection. This course was a real eye-opener for me as well as other staff members.

We currently have six staff members who have taken or are taking the eLearning course. They will act as preceptors and the remaining staff will be brought to competency this month via the "streaming video."

I want to thank you for this opportunity and give a special thank you to Randi and her staff for their dedication to this topic.

Betty Hart RNC-OB

Tempe St. Luke's Hospital - Clinical Coordinator

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EHDI Coordinator's Corner



Early Hearing Detection and Intervention has a Godmother. Her name is Marion Downs. She is 97 years old and the picture to the left is from her Facebook page. How can I be intimidated by the changes in social media, technology and clinical practices if Marion isn't?

More than 50 years ago, she recognized the importance of identifying infants who were deaf or hard of hearing as early as possible. She was responsible for the establishment of the first Joint Committee on Infant Hearing in 1969, which has lead to the current multidisciplinary best practices position statement that guides us today.

Last month she was honored by the CDC as a public health pioneer. Two things strike

me about her story: the role of chance, fate or serendipity; and the character trait of perseverance. Marion chose audiology as her major because the registration lines were the shortest. We were all lucky that day! Although she was convinced that early hearing detection was critical, she didn't have the research or the technology to support her ideas. Despite the challenges, she made early hearing detection and intervention her life goal, and on the way she changed the lives of many generations of children and their families.

Her biographical sketch on her website describes her as relentless in her pursuit to make the identification and management of hearing loss in infants and children an important medical and educational consideration and public health issue. Relentless is an adjective that I really like. It is a little abrasive but describes the ability to envision how things should be and to continue to pursue that vision despite the many obstacles, bureaucracies, challenges and barriers. Relentless also describes a woman who was the #1 tennis player in the United States in her over-90 age bracket. Think what we could do if we were all as relentless as Marion!

Marion Downs is my friend on Facebook. I think I will invite her to "like" the AZEHDI Facebook page. I invite all of you to join us in facing the next set of challenges and in embracing new technology and opportunities.

Lylis Olsen, MS, MPH Arizona-EHDI Coordinator



Is Your Office EHDI-Ready?

Is your office "medical home efficient" with newborn screening (dried bloodspot and newborn hearing screening)? All PCP offices should be a medical home for their patients and it should start from the first day of life of the infant... or even earlier by being involved with prenatal planning. One tool that will help us improve our medical home efficiency will be an EQIPP course that I am helping to construct titled "Newborn Screening: Evaluate and Improve Your Practice." This course fulfills the requirement of the MOC part 4 and will help pediatricians by identifying gaps and barriers within the office and will also offer tips to implement changes to improve newborn screening. This course will become available in approximately 4-5 months and will be available for up to 3 years, so keep an eye out for it.

Bradley Golner M.D. F.A.A.P. EHDITF and EHDI Chapter Champion-Arizona chapter

HiTrack Users:

Please be aware that your password in HiTrack will be changing soon. When prompted in HiTrack, follow the instructions for creating a strong password that only you know. More info will be sent to HiTrack users.

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Fostering Communications between Providers and ADHS

The EAR Foundation of Arizona (EFAz) has expanded its partnership with the Office of Newborn Screening (ONBS) in order to provide outreach and education throughout the state. First and foremost among the outreach/education team's objectives was to address the disconnect between providers and the department regarding all aspects of the screening program: reporting, materials and tools for parents and professionals, updated screening practices and community resources. In response, the outreach/education team developed a standardized Office of Newborn Screening packet that includes information on bloodspot and hearing screening. This informative packet is intended for a variety of health professionals in hospitals and community settings.

In addition to the standardized newborn screening packets, site visits are being offered to assess and improve current screening practices, improve communication with the Department of Health Services, and ensure an effective newborn screening flow within individual systems. Such cooperation in joint outreach training and education are facilitated through these site visits to many different locations in order to update the participating staff on both hearing and bloodspot screening. The education and outreach team has conducted over ten site visits and is scheduled for several more this fall season.

ONBS and EFAz exhibited at several professional meetings and conferences and provided information at numerous events this year. If you would like a visit, presentation or packet please contact the Office of Newborn Screening. If you would like to schedule a site visit of your facility please contact either Sondi Aponte at: Sondi.Aponte@azdhs.gov or Melissa Selbst at: Melissa@earfoundationaz.com.

Healthcare
Providers: Contact
the Office of
Newborn
Screening if you
would like an "inservice" training at
your practice
regarding newborn
screening (hearing
and bloodspot)

Beyond Newborn Hearing Screening

EFAz and First Things First

The EAR Foundation of Arizona has launched a 17 month sensory screening project funded through First Things First Central Region entitled BASICS, or Building a Screening Infrastructure for Children's Success. The EAR Foundation is the grantee and has partnered with VisionQuest 20/20 and the Arizona Childcare Association to develop a project focused on hearing and vision screening at private childcare centers for children aged six weeks to five years. The EAR Foundation has also worked in developing a new, standardized reporting form for First Things First and other community based screening programs in order to meet the 0-3 mandatory reporting requirement. The Office of Newborn Screening is now utilizing this new form and will assess its value. The goal of this project is to help identify children with late onset and progressive hearing loss and vision problems prior to entering school.

T3 and Birth to Three: OAE training update

Lylis Olsen and Randi Winston developed a new T3 module, Birth-3 OAE. Several screening trainings have been held utilizing this new module, including Early Head Start programs. We have also partnered with the Arizona Department of Health Services, Office of Children with Special Health Care Needs, Department of Education Head Start Collaboration Office, and the Arizona Head Start Association, to reach as many EHS and Head Start programs as possible and address the issue of hearing beyond the newborn period. Melissa and Randi have recently conducted several T3 and Birth-3 OAE trainings. To schedule a training offered by one of the EFAz team members or discuss training needs of your staff please contact Melissa Selbst: melissa@earfoundation.com.



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"The prevalence of sensoneural hearing loss in well-babies ranges from 1-3:1000. It is at least 10 times higher for infants in the NICU" -National Center for Hearing Assessment and Management (NCHAM)

Message from the High-Risk Coordinator

Focusing efforts on infants at higher risk for hearing loss is a priority for the Office of Newborn Screening Follow-up program. As many of you are aware, the Arizona Department of Health Services was awarded a grant through the Maternal and Child Health Bureau (MCHB). One of the goals of the MCHB grant is to target infants at higher risk for hearing loss, which is defined as those infants in the Neonatal Intensive Care Unit (NICU) who fail, miss or have an incomplete newborn hearing screen.

My role as the High-Risk Coordinator is to work with hospital discharge coordinators, case managers and/or screening coordinators to identify infants with failed hearing screens and conduct follow-up with parents and primary care providers. The process of identifying and following up with these highrisk infants is a continuous work in progress. We continue to find and refine methods to ensure these infants receive timely follow-up. Thank you to the hospitals who have provided the ADHS staff with NICU census information to help identify these infants.

We also ensure that parents and primary care providers receive the appropriate education

about hearing screening for infants at higher risk for hearing loss. By working closely with hospital newborn hearing screening programs, medical homes and parent guides and parents, we want to achieve the best standard of care for NICU graduates.

Here is a summary of the number of infants at higher risk for hearing loss (those in the NICU who failed the newborn hearing screen) who have received a confirmed hearing diagnosis. The numbers for 2010 and 2011 are preliminary as there are still many cases that need to be resolved.

State Confirmed Hearing Status by Birth Year NICU/Special Care Infants

2009	2010*	2011*
135	110	33

*Preliminary data

Valerie Odeh High-Risk Coordinator





October 14th - Annual Ear Foundation Seminar

The 6th Annual EAR Foundation of Arizona Seminar will be held October 14th at the Phoenix Zoo from 8 a.m. to 4 p.m. The registration fee is \$45 or \$30 for students. The seminar is geared towards audiologists, early intervention staff, speech language pathologists, audiology students, and other professionals that serve speech and hearing needs. You can download registration forms at www.earfoundationaz.com.

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Reporting Hearing Results—Why is it so Important?

What happens when hearing results are not sent or not accurate?

As hearing screening results are reported, ADHS is able to identify infants in need of further screening or diagnostic evaluation, and provide assistance to the primary care physician, and to the family, for follow-up services. If results are not reported to ADHS, primary care physicians and families may not be notified that further testing is required. Each year, several cases are lost to follow-up or lost to documentation. In 2009, 630 infants who failed their hearing screen or were referred for diagnostic evaluation were lost to follow -up. There are quite a few cases in progress for which we are awaiting diagnostic evaluation results, but unfortunately, some providers are not reporting hearing and testing results to ADHS. Reporting is mandated by A.A.C. R9-13-207.

Who should report newborn hearing screening results?

Hospitals

Hospitals report newborn hearing screening electronically using HiTrack. However, screeners must ensure that records are entered correctly in HiTrack. Reporting incomplete results (one ear only), or incomplete demographics information causes delays for the followup team.

Audiologists

Audiologists who perform screening or diagnostic evaluations on infants less than two years of age must report results to ADHS no later than one week after the test is performed. All results must be reported including Normal Hearing results. Reporting forms are available at www.aznewborn.com or by calling (602)364-1409.

<u>Primary Care Physicians and Medical Homes</u>

Physician offices screening infants less than two years must report hearing results to ADHS just as hospitals and audiologists do. Please notify us of any physician offices in your area that provide rescreens so that we can ensure that they are reporting results. Reporting forms are available at www.aznewborn.com or by calling (602)364-1409.

<u>Community Screening</u> <u>Programs</u>

Early Head Start, First Things First, and other community screening programs also must report results to ADHS no later than one week after the screening is performed **for infants less than two years of age**. The screening forms are available at www.aznewborn.com or by calling (602)364-1409.

Who should report diagnosis of hearing loss or normal hearing?

The person or entity who confirmed the hearing loss or normal hearing must reported to ADHS the results

no later than one week after the test is performed.

Where to Report Hearing Results

Hearing results must be faxed to ADHS at 602-364-1495. For reporting forms, please visit www.aznewborn.com.

Why Reporting Is So Important?

Hearing loss is the most common disorder at birth. The intent of Universal Newborn Hearing Screening is to identify infants with hearing loss as early as possible so that appropriate intervention can be initiated. To date, 132 babies born in 2010 have been diagnosed with hearing loss and 48 babies born in 2011 have been diagnosed with hearing loss.

Reporting hearing results for infants less than 2 years of age to ADHS helps identify babies who need further testing, providing better intervention services and reducing the loss to follow-up.

Brigitte Dufour Case Management Coordinator, Office of Newborn Screening



Who should report hearing screening results?

- HospitalsAudiologists
- AudiologistsPrimary Care
 - Providers
 Community
 Screener
 Programs

Visit
AZNewborn.com
for more
information, or
call (602)3641409.



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Babies Do the Cutest Things!

"Look, honey, she's kicking her little legs a mile a minute. Isn't that cute!" New parents beam with pride and joy over their infant's feats. Other times, the baby's out-stretched arms and wiggling fingers go unnoticed while parents are packing lunches and looking for shoes. BABIES ARE ALWAYS DOING SOMETHING. What parents often don't realize is that their baby's cute expressions, gestures and noises are all opportunities to foster language learning.

Parents can learn that their baby's actions are more than just cute: they are communicative. When parents value these actions as language learning opportunities, they give their child a huge language and cognitive boost. Babies with hearing loss, and those at risk of hearing loss, are especially vulnerable to language delays. Any additional language practice, guided by parents, can have an extraordinary impact on these babies.

What is the language learning value of babies' behavior?

EYE CONTACT - Face-to-face interactions between parents and babies through eye contact is a form of early conversation. Babies are learning that looking at the other person is part of a conversation.

EYE GAZE - When a baby looks at something, the parent has the opportunity to talk about that thing. The object of the baby's gaze can be commented on. It's as if the baby is asking, "What does that thing do?" or saying, "That thing is interesting to me," or, "That thing was fun to play with yesterday; I want it again."

VOCAL PRACTICE - Cooing, squealing, and jabbering are essential in developing speech. Babies require practice making sounds.

GESTURES - A baby can gesture "pick me up" before being able to speak the words to express that. Even though the words aren't there, a parent needs to act and respond as if the baby DID say something. A baby's gestures are also useful indicators of her understanding. Studies have shown that when parents gesture, their babies learn better, and the use of gestures in babies is an indicator of future language use.

IMITATION - Parents take great satisfaction when their baby imitates saying "mama" or signing "DADDY." This is an opportunity for parents to expand on language. For example, "That's right! You said doggie! PeeWee is our little doggie. Doggies are so soft. Let's pet our doggie. Nice doggie."

We can look at babies' cute behaviors as future language predictors. A baby may not intend a communication event, but a parent can shape it as such. A baby burps. The parent reacts, "Oh that must make you feel so much better." Use the burp as an opportunity to communicate. If a parent simply treats a burp as a burp, an opportunity to foster language learning has been missed.

Of course, the very nature of parents is to engage and interact with their babies. What we can do as professionals is to point out to parents that what they are already doing naturally has great value in language learning. We can help parents recognize and honor the value of their interactions and encourage them to do it more frequently. Do it early and do it often.

It goes without saying that as we adhere to the Joint Committee on Infant Hearing 1-3-6 recommendations and identify hearing loss early, we are giving parents the great gift of time - time to foster language learning in the critical early months of their babies' lives.

The goals for the EHDI Program are called "1-3-6".

- "1" All infants are <u>screened</u> for hearing loss no later than 1 month of age, preferably before hospital discharge.
- "3" All infants who do not pass the screening will have a diagnostic audiology evaluation no later than 3 months of age.
- **"6"** All infants identified with a hearing loss receive appropriate <u>early</u> intervention services no later than **6 months** of age.

Information for this article is from a seminar sponsored by Arizona Hands & Voices - Guide By Your Side by Mary Alt, Ph.D. CCC-SLP, University of Arizona.

To communicate is a basic human need. The windows of opportunity that open during the first year is critical to language learning.

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ASDB Early Childhood and Family Education Program

The Arizona Schools for the Deaf and the Blind (ASDB) Early Childhood and Family Education Program has been providing services to infants and toddlers who are deaf or hard of hearing since 1974 - well before early intervention services were federally mandated in 1986. Today ASDB is the Part C (of IDEA) provider for infants and toddlers who are deaf or hard of hearing as part of the Arizona Early Intervention Program (AzEIP). This partnership serves the children and families of Arizona extremely well, by providing a centralized point of contact for a full continuum of services.

ASDB provides services to families living all over the state of Arizona. Services are provided in the home or other natural environments. Referrals typically come from local audiologists, but also come from hospitals, parents, and other Early Intervention programs.

Earlier referrals to the ASDB Early Childhood Programs have increased significantly over the past five years due to newborn hearing screening, allowing for improved access to services and support statewide. Referral to both ASDB and AzEHDI at the time of diagnosis is critical for optimal outcomes for children and youth across the state. As indicated in the 2007 Joint Committee on Infant Hearing Position Statement, babies identified with a permanent hearing loss at

birth should be enrolled in Early Intervention by three months and no later than six months of age. In 2009 and 2010, nearly 50% of infants referred to ASDB in Phoenix and Tucson areas were under the age of six months. The efforts being made by audiologists and other professionals in Arizona to send referrals to ASDB in a timely manner have a lasting impact on the lives of these children and their families!

Services to families are based on individual needs, and may include but are not limited to: educational support focusing on language development and general developmental milestones, pediatric audiology, and speech, occupational, and physical therapy as needed. Deaf role models, connections to parent support groups and other parent-to-parent opportunities are available to families. Services are provided at no cost to families on AHCCCS and ALTCS. Families that have private insurance contribute to the cost of their services based on a sliding scale as regulated by the State of Arizona's Family Cost Participation for the Arizona Early Intervention Program.

The incredible benefits of early identification and intervention are more and more evident in the improved lives of ASDB Early Childhood families. Keep those referrals coming!



Earlier referrals
to ASDB Early
Childhood
Programs have
increased
significantly
over the past
five years due
to newborn
screening

Coming Soon! Vital Records Partnership

The Office of Newborn Screening is pleased to announce that soon we will be interfacing with Vital Records to update demographic information in HiTrack. The benefit to you will be a sharing of the most current names, addresses, and phone numbers in the centralized database. It will be important for you to continue to input the mother's name and date of birth, and to submit data in a timely fashion to facilitate this process. We will update you further when the time comes to go live with this project.



OFFICE OF NEWBORN SCREENING

ADHS

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Arizona Commission for the Deaf and the Hard of Hearing

The Arizona Commission for the Deaf and the Hard of Hearing (ACDHH) is a state agency established by the legislature in 1977 with the goal of improving the quality of life of people with hearing loss in the state of Arizona. We work in partnership with the public and private sector and serve as a statewide information and referral center for issues related to people with hearing loss. We award and monitor the contract for the Arizona Relay Service. We also provide free loaned telecommunication devices for people who are Deaf, Hard of Hearing, Deaf Blind, or Speech Disabled. We license American Sign Language interpreters. In addition, our outreach specialists provide free in-service trainings and consumer education presentations throughout the

Every day we respond to dozens of emails and phone calls from people with a wide variety of questions, such as where to get hearing aids, how to advocate for better accommodations in the workplace, where to take sign language classes, or how to choose a school for their child. Several times each year someone will call our Hard of Hearing Specialist, Michele Michaels, to report that a child or grandchild is 2, or 3, or 4 years old and hasn't spoken yet, or has speech that isn't developing normally. Michele always refers these parents and caregivers to the appropriate agencies for intervention and

treatment. The Deaf Specialist, Beca Bailey, is also contacted several times a year with questions about the language development of Deaf children, American Sign Language, schools, interpreters, and related issues.

ACDHH recognizes that it is vitally important that all newborns receive a hearing screening and that parents receive the support they need. Fewer children must be lost to follow-up! Recently our Executive Director Sherri Collins wrote in a letter to the editor, "Early identification of hearing loss in newborns and appropriate intervention before 6-months-old is the most cost-effective way to ensure that children who are deaf or hard of hearing have the opportunity to acquire the language, social and cognitive skills necessary to ensure success in school and later in life." ACDHH will continue to do everything possible to ensure that children and their families receive the support and care they need. For more information about ACDHH, visit our website at www.acdhh.org or contact us at (602)542-3323. You can also visit our Facebook page at www.facebook.com/azcdhh, or follow us on Twitter, @AZCDHH.

Michele Michaels, B.A. Hard of Hearing Specialist Arizona Commission for the Deaf and the Hard of Hearing



"Early identification of hearing loss in newborns and appropriate intervention before 6-months-old is the most cost-effective way to ensure that children who are deaf or hard of hearing have the opportunity to acquire the language, social and cognitive skills necessary to ensure success in school and later in life."

Sherri Collins, Executive Director

Arizona Commission for the Deaf and the Hard of Hearing